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# Chronically Ill Children in America

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The following article has been excerpted from a paper, "Chronically Ill Children in America: Background and Recommendations." The excerpts focus on the background and policy issues while the unabridged paper includes many recommendations.

The paper is a preliminary report of the project, "Public Policies Affecting Chronically Ill Children and Their Families," at the Center for the Study of Families and Children, Vanderbilt Institute for Public Policy Studies, 1208 18th Avenue South, Nashville, TN 37212, telephone (615) 322-8505. The final report, *The Constant Shadow: Childhood Chronic Illness in America*, will be published by Jossey-Bass, Inc., Publishers, San Francisco, CA in 1984.

## Background

### Significance of the Problem

Children who suffer from severe, chronic illness are a neglected group in our society. Their suffering, the heavy burdens they and their families bear, the human resources lost to us all are matters largely unknown to the general public. Chronically ill children live out their lives in a twilight zone of public understanding. As a consequence, our nation, ordinarily attentive to problems of children and families, has lagged in its response to the urgent needs of children with chronic illnesses.

Eleven diseases representative of the severe chronic illnesses of childhood have been examined closely: juvenile-onset diabetes, muscular dystrophy, cystic fibrosis, spina bifida, sickle cell anemia, congenital heart disease, chronic kidney disease, hemophilia, leukemia, cleft palate, and severe asthma. The eleven conditions serve as "marker" diseases, that is, they have characteristics that make them representative of the total range of such illnesses. Considered separately, each disease is relatively rare and occurs in a small percentage of the childhood population. Taken all together, however, perhaps a million children are severely involved and another nine million have less severe chronic illnesses. In considering a million children with severe chronic illnesses, we also refer indirectly to at least three million family members burdened with caring responsibilities, affected by anxiety and sometimes by guilt, strapped by unpredicted expenses and possibly economic ruin, and facing an uncertain future that often includes the premature death of the child.

### Chronically Ill Children as a Class

Chronically ill children can be considered as a class for the purpose of organizing services and allocating resources. The special needs of severely and chronically ill children and their families cannot efficiently and effectively be met simply by extending to this group policies

that are efficient for children with routine illnesses, with acute or even fatal illnesses, with stable handicapping conditions (such as mental retardation), or with mild chronic illnesses such as allergies, transient asthma, and minor gastrointestinal problems.

For several reasons, there has been a tendency to regard each chronic illness separately. Among the reasons are the physiological diversity of the diseases, the variation in the expected length of life, and the diversity of treatments. A result is that each disease has its corps of specialists, its affiliation with specialty clinical centers, its advocacy group, and its champions in the Congress and state legislatures, each competing with the other for scarce funds.

From a policy perspective, however, the diseases have more in common with each other than they do with other illnesses of childhood. We emphasize that not always, but in general, severe chronic illnesses of childhood share the following characteristics. Most of the diseases are costly to treat. Direct medical treatment costs, including hospitalization, may run high, and long-term care may be costly, too: blood and blood products, insulin, syringes, special diets, drugs, orthopedic devices, transportation, long distance telephone calls, oxygen, control of environmental temperature, glasses, hearing aids, special schooling, and nursing care provided professionally or by family members and friends. Most of the diseases require care over an extended period of time; thus costs mount steadily. In acute diseases, costs may be high but for a short period. By contrast, severe chronic illnesses have both periods of brief high costs plus the continuing costs, never low, for a long period of time. The costs of these diseases may be so great that a family can be made bankrupt; insurance may be impossible to obtain; and employment opportunities for parents and family members may be severely curtailed.

Most of the diseases require only intermittent medical care, at the time of diagnosis and the establishment of a treatment regime, at subsequent routine checks, and in periods of crisis. Thus the daily burden of care, day after day, week after week, year after year, falls on the family. Our society is organized to take care of many kinds of handicapped people, young and old, but not the chronically ill child. Formal resources for the daily out-of-hospital care of such children are almost nonexistent. The future course of all the diseases is highly unpredictable. The uncertainty thus generated creates great psychological problems for the child and his family.

Most of the diseases are accompanied by pain and discomfort, sometimes beyond appreciation by the normal individual. Furthermore, most of the diseases require treatments that in themselves are arduous, often painful.

The integration of medical care, not normally a problem, takes on serious proportions when severe and chronic illness of children is involved. The integration of primary, secondary, and tertiary care is essentially nonexistent.

Primary care physicians uncommonly see a child with each of the marker diseases. There may be difficulties in early identification and referral, in allocation of responsibility for continuing care, and for coordination among health providers and schools.

Some states provide treatment for sickle cell disease, some do not; some provide treatment for the complications of diabetes, others do not, thus requiring parents who are fortunate enough to be informed to move to communities where there are tertiary care centers or to states that have policies providing assistance to children with particular diseases. And our nation as a whole simply does not provide, at a cost manageable by most parents, the resources it takes to treat a child with a severe chronic illness.

### Advances in Health Care and Public Programs

Dramatic progress has been made in preventing some diseases, in bringing others under at least a measure of control, and in actually curing some children with certain diseases that were formerly incapacitating or lethal. Much of the progress has resulted from research leading to new knowledge and from technological developments leading to improved treatment techniques.

Examples of achievements in acquiring knowledge and then in putting that knowledge to work through enlightened public policies are: the discovery in 1922 of insulin, enabling the control of juvenile diabetes; research at mid-century leading almost to the elimination of three major disabling conditions of childhood—poliomyelitis, tuberculosis, and rheumatic heart disease; progress within the last two decades in treating renal disease through transplants and dialysis; development of surgical techniques to alleviate some heart conditions and neural tube defects; advances in the treatment of leukemia with chemical and radiation therapies; treatment of hemophilia with the development of cryoprecipitate; development of means to detect various fetal anomalies *in utero* making early intervention possible; and genetic typing and counseling which can improve family planning and reduce the incidence of some chronic illnesses of childhood.

The scientific and clinical achievements have been paralleled in many instances by the development of social structures. They include: the establishment of the Crippled Children's Service in 1935; mandatory immunization against poliomyelitis and other childhood illnesses including public expenditures to insure availability; reimbursement for health care for children through Medicaid, Supplemental Security Income Disabled Children's Program, and Medicare (for end stage renal disease treatment); the Developmental Disabilities Program, extended in the later 1970's to include children with severe and chronic illnesses; Public Law 94-142, the Education for All Handicapped Children's Act, which includes chronically ill children in its definition of handicapped children; basic medical research on severe chronic childhood illness through the National Institutes of Health; and regional correlations between environmental factors and chronic illnesses.

### Chronicity and Severity: Definitions

A general definition of chronic illness is a condition which interferes with daily functioning for greater than three months in a year, causes hospitalization of more than one month in a year, or (at time of diagnosis) is likely to do so.

While the meaning of chronicity can be rather readily agreed upon, defining severity is a much more complex matter. There are simply no good reference points that find ready acceptance. For some of the chronic illnesses here considered, there is a strong inclination among physicians to refuse to assess severity at all, at least not on a physiological basis. For example, either a child has juvenile-onset diabetes or he hasn't, and how well he may be getting along at any particular time is more a reflection of the quality of care and compliance rather than of severity.

For the purposes of this inquiry into public policies affecting chronically ill children and their families, we advance five criteria to assess the severity of impact of an illness, in addition to available criteria of physiologic severity:

- The illness places a large financial burden on the family. For the diseases considered here, out-of-pocket medical cost may exceed ten percent of family income after taxes;
- The illness significantly restricts the child's physical development. Many of the children here considered will be well below normal height and weight as the result of the illness;
- The illness significantly impairs the ability of the child to engage in accustomed and expected activities;
- The illness contributes significantly to emotional problems for the child as expressed in maladaptive coping strategies;
- The illness contributes significantly to the disruption of family life as evidenced, for example, in increased marital friction and sibling behavior disorders.

Defining chronicity and severity on a generic basis to serve public policy purposes is hazardous. The definitions we propose emphasize the social impacts of the diseases in an effort to broaden the conventional disease-oriented definitions. Perhaps most important in considering severity is the recognition that these criteria identify very different groups of children and families. Children with the most physically debilitating arthritis, for example, may have far less emotional problems from the illness than have children with milder diseases.

### The Epidemiology of Chronic Childhood Illness

The dramatic medical advances of the past few decades have meant that many children who would have died precociously of their chronic illnesses now survive to young adulthood. For almost all childhood illnesses, there is little evidence of changing incidence—that is, the number of new cases appearing in a population of stable size. Furthermore, there is evidence that most potential gains in longevity have already occurred. Thus, the number of children with chronic illnesses is presently mainly de-

pendent on the number of new children in the population; and with a stable (rather than growing) child population, the numbers of children with chronic illnesses will also be stable.

About 10-15% of the childhood population has a chronic illness. Among chronically ill children, about 10% (or 1-2% of the total childhood population) have severe chronic illnesses. With the marked decline in morbidity and mortality from infectious diseases among children, and with the increasing survival of children with severe chronic illnesses, the 1-2% have become a much larger part of pediatric practice.

## **The Organization, Costs and Financing of Health Services for Chronically Ill Children**

### **Organization of Services**

Diversity and fragmentation characterize the organization of services for chronically ill children. There is tremendous variation in the care families receive, based on such characteristics as the interest of the specialists in an academic center, the urban or rural nature of the community, and the organization of governmental services, especially Crippled Children's Services. In some areas, a broad variety of family support services are available; in others, available services are limited to medical and surgical interventions.

Families often identify great frustration from the fragmentation of services. They may see one or more specialists a distance from their home; among the specialists, there may be disagreement about plans for the child. Especially for children with multiple handicaps, arranging to be Monday morning in the cardiology clinic, Tuesday afternoon in the neurology clinic, and on Thursday, in the orthopedist's office becomes itself a major management problem.

Despite greater availability, access to adequate specialty medical services is a problem in some communities. Most chronic conditions of childhood are rare and thus community pediatricians and other primary providers, despite the quality of their training, may have little recent experience with an unusual malignancy, severe renal disease, or hemophilia in their practice. Similarly, despite the quality of nursing staff, the hospital with just a few hundred deliveries per year will have very little experience with conditions which occur in perhaps 1 in 10,000 live births. Not only may identification be a complex issue, but referral may be a problem as well.

Access to non-medical services is highly variable. Some communities may have excellent, comprehensive programs for children with specific health problems, such as the comprehensive hemophilia centers in some areas. In other locales primary care providers offer coordination which assures the availability of a broad range of non-medical services to families of children with chronic illnesses. The emphasis on medical and surgical care, to

the neglect of other services for families, can have a great impact on a child's development and functional abilities. As an example, a child undergoing corrective cardiovascular surgery needs attention not only to his medical and surgical care but also to his schooling. What can be done to diminish his falling behind his classmates; what plans should be made for his activity when he returns to school; are home-bound teachers appropriate for a period of time?

Such services can be provided in many ways. Yet the fundamental problem in providing many of them is the lack of reimbursement for the services. Genetic counseling, as an example, is often dependent upon federal research or service support, and with cyclical variations in the support, genetic services may come and go in a relatively brief period of time.

### **Costs of Care**

For most children in the United States, health care costs are small. Average yearly health expenditures for children not living in institutions were only \$286.07 in 1978. This average figure, however, disguises a distribution that is extraordinarily skewed. Most children incur minimal health care expenses; relatively few require care that costs an enormous amount. For example, only 5.4 percent of persons under 17, many of whom were chronically ill, were hospitalized one or more times in 1978, at an average cost of \$1,920. The rest of the childhood population had no hospital expenditures at all. There are also many chronically ill children in the 2 percent of the nation's population that uses over 60 percent of all inpatient resources each year.

The typical pattern of a high-cost childhood chronic illness involves a series of out-patient treatments and hospitalizations over many years together with routine daily home-care or self-care procedures. This pattern generates many obvious medical costs, for hospital and physicians, medications, lab and X-ray services, and often for such services as physical therapy or social work. Many costs not easily categorized or assessed are also generated; these include transportation costs, extra telephone costs, costs associated with time lost from work or school (often referred to as lost opportunity costs), costs for special diets, and emotional costs associated with increased worry and stress within the family. For each illness the specific medical and social-emotional costs will differ, but for almost every family, both types of cost will be major factors in the financial picture.

Though chronically ill children represent a segment for society for which health care costs are disproportionately high, information available on the costs and financing of services for these children is sparse. For example, no studies are available to enable comparisons across many illnesses and that also take account of the wide range of family needs related to the illness. Instead, most studies focus on specific illnesses and generally on medical services, excluding other services equally relevant to care but often delivered outside of medical settings.

## Financing of Care

The system for financing health care in this country is a potpourri of federal programs, state programs, and private insurance arrangements. The complexity of the system is particularly frustrating for parents with a child whose existence is dependent both on specialized medical procedures and on general health services. While most chronically ill children have a large portion of their medical care supported by some third-party arrangement, there remain large gaps in coverage. For some families these gaps can be financially ruinous. We present below a discussion of the six primary sources of payment for health care (broadly defined) of children with chronic illness: private insurance companies; disease-oriented voluntary associations; Medicaid; state Crippled Children Service programs (CCS); special state programs; and out-of-pocket monies.

- **Private Health Care Insurance.** Approximately 75 percent of the nation's children are covered by some form of private insurance. Most children (68 percent of all children) receive benefits under group plans, usually covered as dependents of employed parents. These general figures might suggest that most of the nation's children are adequately protected. A closer look, however, reveals several major shortcomings of private health care insurance, particularly in relation to chronically ill children.

First, private health care insurance is actually medical care insurance. Private plans are designed to cover hospital and physician costs, some lab and drug costs, and a few additional services. They do not cover many costs that families with a chronically ill child will generate, including costs of transportation, home renovations, compensation for time lost from work by parents, custodial care, or counseling.

A second serious drawback of private health care insurance involves the various exclusions embedded in most plans.

Perhaps the most important limitation of private health care insurance is simply the fact that it does not cover many Americans; it especially does not cover children who have limitations in activity and who live in families whose income is below the poverty line. Of these children (numbering about a million), only 17.5 percent are covered by private insurance. The rest are either uninsured or covered under public programs. Furthermore, the number of children, chronically ill included, who are not covered by private insurance tends to increase substantially during periods of high unemployment, when families lose coverage under group plans and cannot afford the costly premiums of an individual plan.

- **Medicaid.** The largest health care financing program that involves children is the Medicaid program, also known as Title XIX of the Social Security Act. (Medicaid is a larger number of dollars but touches only a group of children; those with end-stage renal disease are jointly funded by federal and state governments, as all states to pay for certain services for children and allows states to pay for any of an

additional 27 services. Eligibility requirements, in many states, are tied to the nation's major welfare program, the Aid to Families with Dependent Children (AFDC) Program. In these states, to be eligible for Medicaid, a family must first be enrolled in the AFDC program.

Some states have elected the "medically needy" option, an important one for chronically ill children. Under this option, families with dependent children or with one absent, unemployed, or incapacitated parent can qualify for Medicaid even if the family income is above the Medicaid cutoff point, but only if the family's income falls below the cut-off point when medical expenses are subtracted. Even in states that offer this option, actual implementation has been spotty.

Many chronically ill and disabled children living in low income families are not eligible for Medicaid. Forty percent of all the nation's disabled children in poverty are not eligible for Medicaid. Twenty-two states have Medicaid programs that cover at least half of the low income handicapped children; 27 state Medicaid programs do not cover even half of this population. If a low-income chronically ill or handicapped child is eligible for Medicaid, it is likely that the program will pay for only some of the services that he or she will need.

- **Crippled Children's Service (CCS).** The CCS program started in 1935 and was the only major public source of support for the care of low-income chronically ill children until the early 1980's, when Medicaid and a variety of categorical programs began. The original legislation established federal grants for states that states would then match.

In August 1981, Congress established the Maternal and Child Health Block Grant and in so doing removed all federal statutory requirements for a state CCS agency. In most states, CCS agencies continue to exist because of state legislation but they all have substantially less federal monies (although not necessarily less state monies). In these states, the CCS program still plays a major role in the care of chronically ill children. It sets and disseminates standards of care, provides for a fairly broad set of services, and covers children from a wide range of income levels. At its best, the CCS program represents an arena in which both the organization and the financing of care merge. It is the only broad-based child health program to have influence over both sides of the child health care coin.

The CCS programs have provided much care to many children with chronic illnesses. About \$280 million dollars were spent by CCS agencies in 1979; of this amount, 31 percent (\$86 million) were federal monies. CCS programs served about a million children in 1979. Data from a recent survey show that in 1980, state CCS programs served 0.91 percent of the nation's children, compared to 0.33 percent in 1948.

- **Disease Oriented Voluntary Associations.** Almost every childhood chronic illness has an associated advocacy group. The origin, scope and available resources of these organizations vary widely. For example, the Muscular Dystrophy Association spent \$56.8 million in 1979; the

Cystic Fibrosis Foundation spent \$11.6 million in 1980; the Leukemia Society \$3.6 million in 1980.

These organizations also allocate varying amounts of money to medical services, patient education and training. As a whole, they tend to pay for services that are not reimbursable within the usual system of care, such as special prostheses, recreational activities, or transportation. There is little specific information available regarding how many children are served or how much is spent per child by the voluntary foundations.

Perhaps the most important role that they play, however, is one of advocate. In the past they have supported state CCS programs, often persuading state legislatures to spare the CCS program. For this reason, these organizations may be crucial actors over the next few years, as state legislatures exercise the freedoms given to them by the Maternal and Child Health Block Grant. On the national level, they have often played a critical role in supporting Federal research expenditures in their areas of interest.

- **Out-of-pocket expenditures.** Regardless of the type and extent of coverage that parents may have for their chronically ill child, out-of-pocket expenditures can be high and unpredictable. Families with a child with asthma spent an average of 14 percent of family income on medical costs. In a survey in 1980, the Cystic Fibrosis Foundation found that 20 percent of the respondents reported out-of-pocket costs greater than 30 percent of family income; more than half the respondents said that these expenses were greater than 10 percent of family income. A study of families with children with spina bilda revealed that the average out-of-pocket expenses were 12 percent of the family income. When income loss and nonmedical costs were included, out-of-pocket expenses were 25 percent of family income.

- **Special state programs.** Prior to the introduction of the Maternal and Child Health Block Grant, the federal government had a series of categorical grants to states for child health programs, several of which related directly to chronically ill children. The Hemophilia Treatment Center projects and the Genetic Diseases programs are two examples. Although the monies involved in these programs tended to be small, they often provided important seed or ancillary money for state-initiated model programs. In 1980, state hemophilia centers, designed to provide comprehensive care to patients living in an identified region, spent almost \$8 million. In fiscal year 1979, the federal government appropriated \$11.7 million to the Genetic Diseases Program.

These federal programs do not exist as independent programs any longer but there are many state programs, offspring of the federal initiatives, that are continuing. In addition, several diseases have associated state-initiated programs. There are, for example, cystic fibrosis programs operating in several states, developed usually from advocacy efforts spearheaded by local chapters of the Cystic Fibrosis Foundation. There are few data on any of these state-based categorical programs, or on the number of children and families that they serve. Yet, in some states they represent an important, albeit small,

source of support for health care of chronically ill children.

## Principles for Public Policy

Policy concerning chronically ill children should address the gaps between the special needs of the children and their families and the characteristics of the health care system. The project has identified certain basic principles which should underlie policy, regardless of specific organizational and program characteristics.

- Children with chronic illnesses and their families have special needs which merit attention, beyond that provided to the health needs of able-bodied children. Improvements in health services in general will improve the lot of chronically ill children, and policy development for chronic childhood illness should be integrated with other developments in national child health policy. Nonetheless, the special needs common to most children with chronic impairment will continue to need special attention in public policy.
- Families have the central role in caring for their own members and the goal of policy should be to enable families to carry out their responsibilities to nurture their children and encourage their most effective development.
- Services should be distributed in an equitable and just fashion, specifically excluding from the distribution formula such nonfunctional characteristics as race, sex and socioeconomic class.
- Policy should ensure that a broad array of services is available to families with chronically ill children—beyond the usual medical-surgical or health services.
- Policy should encourage professional services of a highly ethical nature. Key elements include truth telling, confidentiality, maintenance of dignity and respect for family preference, professionals' recognition of limits of their own effectiveness, and emphasis on collaboration.
- Chronically ill children should stay on task in school to the greatest degree possible. Schooling is the main occupation of young people, and the interference of illness and its treatment with educational activities should be diminished.
- The public commitment to sound basic research has resulted in tremendous advances in the health of chronically ill children. Policy should encourage the continuation and expansion not only of biological research, but also of psychological, biosocial and health services research related to chronic illness in childhood.

## Issues to be Considered for Change in Existing Policies and Programs

### Issues: Organization of Services

- The specialization that has improved the medical outcomes for chronically ill children has resulted, ironically, in fragmentation of medical services. The lack of coordination of services, not normally a problem in the care of children with acute illnesses, takes on serious proportions when there is severe chronic illness.
- The diverse providers who treat an individual child infrequently coordinate their efforts. Caregivers may

change over the long haul of the illness and its often complex treatment. Families often lack supportive counseling in the care and management of the child with chronic illness.

- Public programs such as those supported by the Crippled Children's Service, Medicaid and the federal research agencies, provide many essential services to chronically ill children. Yet they often favor the provision of high technology services (usually at high cost) and neglect relatively the broad base of services needed to maximize child functioning and family potential.

#### Issues: Costs and Financing of Services

- Children with chronic conditions, particularly those with functional disabilities, require much greater than average use of hospital and ambulatory care. In 1977, chronic conditions accounted for 36 percent of total hospital days for all children less than age 15 in the United States. Similarly children limited in activity had greatly increased use of hospitals and visited the doctor more than twice as much as other chronically ill children.

- Public programs account for half of all expenditures for the care of chronically disabled and chronically ill children. Clearly the combined effect of simultaneous reductions in these programs—Medicaid, Medicare and the Maternal and Child Health Block Grant (Crippled Children's Service)—is very serious for chronically ill children.

- The distribution of payment for the medical care of chronically ill children is capricious. There is great variability of financial coverage by income, condition, severity, type of services and geography. The gaps in coverage are of several types:

- Gaps in benefits. Many programs fail to reimburse for services used frequently by chronically ill children—transportation, social services, home care materials, and genetic counseling.

- Gaps in populations covered. 10% of all children with functional limitations have no insurance, public or private, and 20% of low income children with functional limitations are uninsured.

- Gaps in public programs. Medicaid covers only 25 percent of the disabled child population and only about 60 percent of disabled children below poverty. State variation in Medicaid eligibility and scope of coverage for disabled children is tremendous.

Large variations exist between CCS programs in numbers of children served, generosity of state programs and conditions eligible for treatment. The Supplemental Security Income program, another important federal program for the disabled population, covers few children; only 5% of SSI beneficiaries are children.

- Gaps in private programs. The role of private voluntary health associations in financing care for disabled children is limited to "insurers of last resort."

- are not covered by private insurance are almost twice as much as coverage. While private insurance covers all children, it does

#### Issues: Schools

- Education serves a number of important functions in all children's lives, and its significance for children who have special problems cannot be overestimated. Many chronically ill children evidence no unusual learning problems but many require medical and physical accommodations to participate in school. Under P.L. 94-142, they need "related services" without needing "special education"; yet by definition there can be no related services without special education.

- Chronically ill children may need specialized instruction (e.g., vocational and career preparation, or even adaptive physical education, nutrition, and care of appliances) in addition to instruction in traditional academic areas. These needs are considered by many teachers and administrators to be outside the purview of the public schools. Professional preparation programs for handling medical matters in the classroom are unavailable for the most part.

- Teachers' attitudes regarding expectations for academic achievement by chronically ill children often result in exaggerated deference to the medical implications of a child's handicap. The teacher, the parent, and the physician may have different and sometimes incompatible goals for a chronically ill child.

- Development of plans for children with special health needs is limited too often by calling for services that are available already in a school system rather than for services the child actually needs. Costs to local education agencies, which have assumed the provider functions, are cited as a deterrent to provision of a broad range of health services that may be needed.

- A major educational problem of chronically ill children is frequent or occasional interruption in school attendance, from prolonged hospitalization, regular weekly treatments, or unpredictable three or four day absences. Current home and hospital school programs, often the only means of providing educational services to sick students, are characterized by great diversity in rules, requirements, and quality. Rigidity in absence requirements for eligibility for home programs and brief length of teacher time on a weekly basis (most states require only three hours per week) illustrate some of the problems.

- The need for supportive services in school complicates educational placement and programming decisions for chronically ill children. Service needs may include special diets (for students with asthma, diabetes, or advanced kidney disease), physical therapy and special transportation (for students with rheumatoid arthritis), special physical handling (for students with spine bifida or muscular dystrophy), social work and liaison services, counseling, and in-school administration of medicines and treatments such as catheterization.

- Schools have limited health services for all children, and few education authorities have developed and implemented specific policies and program health standards for children with special needs.

- Chronically ill children in school have great need for emotional support and opportunities to experience normal peer relationships. Some of the obstacles to meeting these needs include:

- erratic attendance patterns



- maladaptive social behavior
- embarrassing side effects of specific diseases
- isolation due to equipment needs or geographic location. Perhaps the most important obstacle is the unavailability of support for parents in coping with chronic illness.

#### **Issues: Research**

- The dramatic improvements in the treatment of many chronic illnesses in the past quarter century have in large part come as a result of a sizeable investment in basic biomedical research, mainly through the National Institutes of Health.
- Support for basic biomedical research has plateaued in the past few years, diminishing the rapid growth in new knowledge characteristic of the previous two decades.
- Support for basic research in other disciplines critical to the needs of families with chronically ill children has been far less generous; investment in behavioral sciences research represents a minimal percentage of the NIH effort in chronic illness. Even less support has been available in such areas as health services and nursing science research.

#### **Issues: Training of Providers**

- Most health providers, regardless of discipline, have limited experience with chronically ill children during training. Pediatricians, health professionals with perhaps the greatest direct experience with childhood illness, are mainly exposed to the acute exacerbations of chronic conditions and only occasionally to the long-term problems and family aspects of chronic childhood illness.
- Public health practitioners provide leadership of Crippled Children's and related programs. Yet their training is often divorced from the places where chronically ill children and their families seek health care. The separation of public health people from the clinical realm has led to some of the fragmentation of services for children and diminished the likelihood of effective public-private collaboration in program development.
- Faculties of key professional schools (e.g., medicine, nursing, psychology, social work) rarely include members whose academic focus has been the broad problems affecting families with chronically ill children. Faculties may include many disease specialists, but rarely generalists interested in chronic childhood illness, its coordination or family implications.

# National Council on the Handicapped Formulates a National Policy for Persons with Disabilities

The National Council on the Handicapped has developed a National Policy for Persons with Disabilities with the participation of members of the disabled community, government, the service provider professions, and the private sector. Drafting meetings were held in each of the fifty States and the District of Columbia, in addition to extensive mail, telephone and computer communication. A copy of the policy statement was sent to President Reagan on August 29.

Full text is provided for the 22 principles set forth in the Council's national policy document, but only excerpts of the text elaborating on each principle are included. Readers interested in obtaining the entire document or wanting to comment on it should write directly to: National Council on the Handicapped, Mary E. Switzer Building Room 3116, 330 C Street, S.W., Washington, DC 20202.

## National Policy for Persons with Disabilities

1. **AREAS OF RESPONSIBILITY:** Laws, regulations, policies and programs which enable people with disabilities to achieve maximum independence, self-reliance, productivity, quality of life potential and equitable, mainstream social participation shall be initiated, funded, administered and promoted by government and the private sector.

The Federal Government has significant, continuous responsibilities to initiate, fund, administer, coordinate and regulate effective, socially and fiscally responsible programs which are designed to assure disabled people of all ages uniform services in all parts of the nation and full and productive participation in the mainstream of society. These responsibilities shall be fulfilled in such a way that state and local efforts to meet particular, often unique, needs are supported and facilitated rather than restricted and hindered. The Federal Government further has primary responsibility to guarantee and enforce the rights of disabled people according to the letter and spirit of the United States Constitution and of applicable laws and regulations.

2. **EDUCATION:** Free and appropriate public education in the most productive and least restrictive environment shall be available to all disabled children and adults.

Educational programs should be operated principally at the state and local levels, with regulatory, coordinating and fiscal involvement by the Federal Government as necessary to guarantee the basic rights of disabled persons, including individuals with severe disabilities, to free, appropriate, equal and integrated educational opportunities.

3. **ATTITUDES:** Realistic, positive perceptions of disability and affordable, productive approaches to the problems and potential of disabled people should be effectively communicated to all citizens by all educational and mass communication media.

The communication of realistic, progressive perceptions of the problems and potential of disabled people should be continually included in the curriculum at all public and private education.

abled persons, to the maximum extent possible, should have the principal responsibility to solve their own problems and fulfill their potential.

Disabled individuals should play leading roles in creating, making policy for, administering and directing public and private disability-related programs at the international, national, state, local, and individual levels.

5. **EMPLOYMENT:** Employment and productive involvement of individuals with disabilities should be effected in all major functions of society, including at policy-making and administrative levels, and in disability-related service programs.

A mechanism should be established to link disabled job seekers with available positions locally, state-wide and nationally, and to appraise employment trends for more effective vocational planning. Disabled people should receive equal pay for equal work.

6. **DEMOGRAPHIC INFORMATION:** Accurate demographic information in regard to disabled people and their needs should be developed and updated on a regular basis.

7. **SINGLE POINT OF ENTRY:** A single point of entry for information, referral, advocacy and counseling should be available in every community. This entity should be responsible for offering to each disabled person comprehensive information in regard to an efficient, unbiased continuum of human services delivery systems.

Such information, referral and counseling entity should be operated by and through the cooperation of state and local government and/or the private sector, with certain coordinating, guidance and regulatory services provided at the federal level.

8. **LAW:** Government and the private sector should cooperate to develop a comprehensive, internally unified body of disability-related law which guarantees and enforces equal rights and provides opportunities for individuals with disabilities.

These could include and would embody the spirit and intent of Title V of the Rehabilitation Act of 1973, P.L.

ED PERSONS: Dis-

93-112 as amended; of the Education for All Handicapped Children Act, P.L. 94-142; and of the Developmental Disabilities Assistance and Bill of Rights Act, P.L. 94-103; and shall be vigorously and efficiently enforced. Congress and the executive branch should act forthwith to include persons with disabilities in the Civil Rights Act of 1964, the Equal Opportunity Act of 1972 and other civil rights legislation and regulation. In matters of fundamental human rights, there must be no retreat.

9. **ACCESSIBLE COMMUNITIES:** Government and the private sector shall encourage and cooperate with initiatives to establish efficient, architecturally and communicatively accessible, fully integrated communities and services which utilize the available psychological, social, economic, architectural and technological knowledge to make the best our culture has to offer efficiently and cost effectively available to all people.

Access to public and private facilities and programs should be according to a comprehensive, equitable, uniform national code, which includes mechanisms for vigorous enforcement and which does not impose counterproductive requirements on individuals and organizations.

10. **FISCAL RESPONSIBILITY:** Disability-related programs shall be conducted with fiscal responsibility and sound management principles.

11. **INDEPENDENCE INCENTIVES:** Disincentives to employment and to full social involvement shall be replaced by a comprehensive system of independence incentives and investments in the productivity of persons with disabilities.

Possible incentives include new and increased tax deductions, tax credits, subsidies and guaranteed and/or low interest loans for individuals, families and organizations making investments which increase the productivity of persons with disabilities.

12. **RESEARCH:** Productive, coordinated research in the area of disability and the development of efficient, cost effective, independence-oriented technology and service delivery should be promoted, funded and made available for universal utilization by government and the private sector.

The Federal Government should take the lead in promoting and coordinating such activities, and in ensuring that appropriate incentives are provided and adequate funds are allocated.

13. **PREVENTION:** All citizens should be encouraged and assisted in their efforts to prevent and to minimize the negative effects of primary and secondary disability.

The resources and technology are available for the United States to mount an effective national program to promote better disability-related and health education and to prevent accident and illness. In order for such an effort to be successful, the cooperation and coordination of the services and activities of many individuals and agencies in the public and private sectors are necessary.

14. **COORDINATION:** Effective mechanisms to plan and coordinate government, private and voluntary disability-related activities should be developed at the federal, state and local levels.

The very great potential of America's disabled citizens will not be fulfilled until disability-related activities are planned and executed as a coordinated, integrated unity.

15. **EVALUATION:** Guidelines for policy and program evaluation systems should be established for monitoring and assessing the effectiveness of disability-related programs.

16. **PRIVATE SECTOR INVOLVEMENT:** Private sector involvement in the development of effective solutions for the special problems of disability should be encouraged and increased.

17. **VOLUNTEERS:** All persons, including people with disabilities and their private organizational and individual supporters, should be encouraged and assisted to participate on a nonpaternalistic, voluntary basis in public and private efforts to enable disabled people to achieve their maximum quality of life potential.

18. **QUALIFIED PERSONNEL:** An adequate number of qualified personnel should be trained at all levels to provide more effective services for disabled people.

19. **CONTINUUM OF SUPPORT SERVICES:** Government and the private sector shall develop, establish and support a family and community based continuum of residential, counseling and support services which serve as useful alternatives to traditional long term care institutions and make a broad range of affordable, independence and productivity oriented options available to every disabled person.

20. **RURAL AREAS:** The unmet needs of disabled persons living in rural areas shall be examined carefully, and appropriate services shall be developed, funded and executed by government at all levels and by private sector entities.

21. **ETHNIC AND SOCIAL MINORITIES:** Government and the private sector must cooperate to ensure that adequate services and opportunities are available to disabled members of ethnic and social minorities.

22. **INTERNATIONAL COOPERATION:** Government and the private sector should cooperate to support and learn from the efforts of the world's more than 500 million persons with disabilities as they strive to achieve their maximum quality of life potential and equitable mainstream social participation.

### **Working Together for an Accessible Society**

Optimal solutions for disabled people will require cooperative working relationships among all citizens and groups—including individuals, families, communities, and private sector and all levels of government—and responsible, positive, unified advocacy based on the universal human values which we all share.

## DOT Proposes New Mass Transit Rule

The Department of Transportation (DOT) has published a notice of proposed rulemaking (NPRM) intended to ensure the provision of transportation services to handicapped persons in DOT-assisted mass transit programs without imposing undue cost burdens on recipients. The proposed rules would carry out Section 504 of the Rehabilitation Act of 1973 and Section 317(c) of the Surface Transportation Assistance Act of 1962. The NPRM was published in the September 8th *Federal Register* with a comment period ending November 8 (extended to December 8 in the October 31 *Federal Register*).

How to ensure the provision of adequate public transportation for handicapped persons at a reasonable cost has long been a difficult problem. At the present time, DOT requires recipients of Urban Mass Transportation Administration (UMTA) assistance for mass transit programs to make "special efforts" to provide transportation for handicapped persons. Section 317(c) of the Surface Transportation Assistance Act directs the Department to publish a new regulation that includes "minimum criteria for the provision of transportation services to handicapped and elderly individuals," and requires that the rule provide for public participation in the establishment of programs to provide services for handicapped persons and for DOT monitoring of recipients' compliance.

Under the new NPRM, a recipient could meet its obligations for services to handicapped persons in three basic ways. It could make 50 percent of its buses accessible (e.g., through the use of lifts), it could establish a paratransit or special services system (e.g., a "dial-a-ride" van system), or it could establish a mixed system that would combine elements of accessible bus and paratransit service. The NPRM would not require existing subway systems to be made accessible.

Whatever kind of system the recipient establishes, the system must, subject to the "cost cap" described below, meet six service criteria. The system must serve the same geographic area as the recipient's service for the general public, at the same time, and at comparable fares. There cannot be waiting lists for eligibility or restrictions or priorities based on trip purpose. Finally, the waiting time for service must be reasonable.

In order to avoid imposing undue financial demands on recipients, the NPRM proposes a "cost cap." (A Federal court said a previous DOT Section 504 rule exceeded the Department's authority because it imposed undue costs.) This cost cap is a ceiling on expenditures that a recipient is not required to exceed. However, decisions on the service tradeoffs that are made in order to keep costs within the cost cap must be made through the public participation process described below. The NPRM requested comment on two alternative approaches to setting the cost cap: either 7.1 percent of the recipient's UMTA assistance, or 3.0 percent of the recipient's total operating budget.

Within nine months of the effective date of the final rule, each recipient would be required to have a program for providing transportation services to handicapped persons. During that time, the recipient would plan its service in consultation with handicapped persons and groups representing them. A public hearing would be held, and the recipient would receive comments during a 60-day period and respond to comments. The recipient's program and information concerning the public participation process would be sent to UMTA for approval. An annual report to UMTA would be required from each recipient.

After the close of the comment period on the NPRM (December 8), final rules will be drafted. The final rules require Department-level approval at DOT, and clearance through the Department of Justice and the Office of Management and Budget before publishing.

For further information, contact: Robert C. Ashby, Department of Transportation, 400 7th Street, S.W., Room 10105, Washington, DC 20590, (202) 426-4723 (voice) or (202) 755-7687 (TTY). Copies of the NPRM are available on tape for visually impaired persons.

## MR Institutions Face Possible Fund Loss

Secretary Margaret M. Heckler of the Department of Health and Human Services (HHS) recently took a further formal step toward a possible cut-off of millions of dollars in federal funds for seven Massachusetts state institutions for the mentally retarded. The Health Care Financing Administration (HCFA) was directed to assemble a federal survey team comprised of health, mental retardation, and fire safety professionals.

After coordination with state officials, the team was directed to conduct surveys at the institutions to assess the extent to which the schools are in compliance with federal standards. Heckler also insisted that parents of the mentally retarded residents be consulted and consideration given to their concerns.

Five of the seven schools have been involved in litigation before Federal District Judge Joseph L. Tauro since 1972 due to deficient conditions at the facilities. The problem areas primarily involve fire safety and the privacy of living areas.

After the facilities were visited last summer by Ms. Heckler or her personal representatives, she said, "This is not a new problem ... it has gone on for ten long years ... the time to remedy these deficiencies has absolutely run out." She noted that although much improvement has been made over the years, "there still remain several compliance problems and I earnestly hope that the state legislature will take action in September or October to appropriate funds necessary to achieve full compliance with federal regulations."

(See MR Institutions, page 20)

## Transition from School to Work

The theme for this year's celebration of "National Employ the Handicapped Week" in the Department of Education was the transition of disabled persons from school and training centers to the work place.

In his introductory remarks, Secretary Bell stressed that schools must strive for increased enrollment of handicapped students in vocational education classes. This idea was underscored by Stephen Chitwood from the Parent Educational Advocacy Training Center, Alexandria, VA, who pointed out that according to statistics gathered in a 1982 report only 4.3 percent of secondary students in vocational education were handicapped students. Dr. Chitwood described how successful the training of parents has been to be advocates and to work with teachers and school staff on procedures affecting their handicapped children. He now envisions a second phase of parent training—focusing on vocational aspirations of their children and becoming knowledgeable about laws and opportunities. A 15-hour course for parents is now being developed by the Center to help parents work with schools to fulfill the promise of P.L. 94-142 of preparing handicapped students for work.

Margaret Collins and Pamela LeConte from the Anne Arundel County Public Schools in Maryland described a program of how one school system attempts to smooth the transition of handicapped students to work. Students are referred by teachers, parents, or counselors to the program which provides a vocational evaluation in a center or laboratory to arrive at a realistic diagnosis. A Vocational Support Team follows through by giving both vocational education teachers and students (and if desired, parents) continuing help after the vocational plan is developed. Self-confidence and good work habits are stressed along with the acquisition of work skills. The Vocational Support Team said they found vocational educators ill prepared to work with handicapped students, but that they gladly avail themselves of the services offered which include adapting equipment to the needs of the students.

Paul Wehman from the Education Services of Virginia Commonwealth Services reported on his project which places moderately to severely mentally retarded individuals in competitive employment. This program works with people whose mean IQ is 45 and who as a rule cannot read, write or compute. The project has placed 150 program participants in food service, custodial and landscaping businesses. Success is only claimed if the employment last six months or more. Wehman's program found the biggest obstacles to integrating these severely retarded people into the real world of work are overprotective parents and transportation problems. A key to success is involvement of employers in the program and creation of a buddy system among coworkers.

For more information about the three programs described above, contact each program directly:

Stephen R. Chitwood  
Parent Education Advocacy Center  
228 S. Pitt Street, Suite 300  
Alexandria, VA 22314  
(703) 836-2953

Margaret Collins  
Vocational Support Service  
Annapolis Junior High School  
1399 Forest Drive  
Annapolis, MD 21403  
(301) 287-8476

Paul Wehman  
School of Education  
Virginia Commonwealth University  
Richmond, VA 23264  
(804) 257-1305

The Department's celebration continued with a panel entitled "Outstanding Post-Secondary Education Programs Focusing on the Transition of Disabled Students from School to Work." Presenters of the panel highlighted the need for colleges and universities to offer specialized services to persons with specific disabilities which would assist them in successfully completing their education.

Two of the presenters, Jake Meneses and Diane Pereira, described the many services offered to disabled students at Marist College in Poughkeepsie, NY.

Disabled students are identified upon entering the school. Support services may include instructing faculty members concerning the limitations posed by various handicapping conditions along with helpful suggestions for overcoming them.

Some of the disabled students at Marist College have been successfully involved in the college's Cooperative Education Program. Under this program, students work for a semester as paid interns in businesses throughout the country.

The second panel, "Adult Education/Vocational Rehabilitation Linkages for the Disabled Person," described ways in which adult basic education (ABE) programs can benefit disabled adults.

Nancy Pollock, from Gallaudet College's ABE program, discussed the ways in which this program assists deaf individuals in the Washington, DC, area. The program offers evening courses in reading and arithmetic to hearing-impaired persons over the age of 18. The courses are designed to prepare students for high school equivalency testing and to increase job readiness and enhance basic skills which can lead to on-the-job promotion for those already employed. Other courses involve training in independent living skills and sign language for family members.

ABE also plays an important role in vocational rehabilitation, according to Rosemary Lareau of the Maryland Rehabilitation Center in Virginia. ABE programs at these centers are offered to clients in conjunction with special-  
(See Transition, page 14)

## The Human Exhibit

On Thursday, October 20, the Columbia Lighthouse for the Blind in Washington, DC, conducted a novel employer-awareness workshop, "Job Exploration for Employers." Unlike most meetings of this type, in which the majority of the exhibits unveil the latest in high technology, this gathering displayed people.



"Human Exhibit" Donald Barrett, Information Specialist at the Clearinghouse on the Handicapped, is shown above with Barbara Pegg (right), also from the Clearinghouse, and Theresa Travis, Director of Rehabilitation at the Columbia Lighthouse for the Blind.

Approximately 25 blind people gathered together in one of the Lighthouse's conference rooms to share information about their jobs with employers in the Washington area. A wide range of professions were represented by the blind participants—computer programming, electrical engineering, musical accompaniment, systems analysis, law and others.

The setting was informal and visiting business-people were encouraged to circulate freely among the participants, asking questions. Most of the employers took full advantage of this opportunity—many of them had little or no previous contact with blind persons. Questions such as: How did you learn to type? How did you get your job? How can we learn what a blind person can and can't do? and How would you handle our type of work? were asked and answered many times that day.

The Lighthouse staff believes that by providing a forum where prospective employers can freely interact with visually handicapped individuals, many preconceived erroneous ideas about blindness and its limitations can be dispelled.

This meeting allowed employers to find out firsthand about the capabilities of disabled persons in employment from the people who know best.

Said one participant, "If you're thinking about hiring a blind person and you aren't sure he/she can handle the job, ask the person who can give you the best answer—a qualified blind person."

## Spotlight on Child Abuse And Disabled Children

The plight of abused and neglected children who also are handicapped has become increasingly a concern of parent organizations and professionals who work with handicapped children as well as Congress and Federal agencies that provide funds for programs to serve children. Several new developments show a trend toward identifying and increasing services for these children.

### New Project to Serve 5-8 Year Olds

Under a new ED-HHS project, teachers of school-aged handicapped children will be trained in detecting and preventing abuse and neglect of disabled youngsters. The training program was announced as part of a \$400,000 project jointly sponsored by the Department of Education (ED) and the Department of Health and Human Services (HHS) to improve services to young handicapped children.

With \$300,000 from ED's Special Education Programs and \$100,000 from HHS's Administration on Children, Youth and Families, the project will involve 15,000 public school systems in a program of prevention of abuse and neglect of handicapped children aged 5 through 8.

Training materials for public school teachers and officials will be adapted from a child abuse and neglect program developed for abused or at-risk children in Head Start programs. Ten percent of the children enrolled in Head Start, which served 400,000 children this year, must be handicapped. The new project will also tap the services of six Resource Access Projects which provide training and technical assistance to aid Head Start programs serving handicapped children.

Five university affiliated facilities, which offer training for those who work with the developmentally disabled, will also help develop materials for the program.

In announcing the kickoff of the new project on September 23, Medeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, said the project is focusing on abuse and neglect among handicapped children because "we do know that handicapped children are a greater physical and emotional burden (for parents), especially when there aren't enough support services."

In addition to the child abuse prevention effort, money for the project will be used to update eight manuals used for

mainstreaming handicapped children in Head Start programs. The manuals will be supplemented with audiovisual training materials to help Head Start teachers work more effectively with handicapped children.

Before use in the 15,000 public school systems beginning in the fall of 1984, the projects will be field-tested in Boston, MA, Chapel Hill, NC, Portland, OR, Kansas City, KS and Washington, DC.

#### Conference on Child Abuse

In late September, more than 2,000 social workers, educators, members of the health and legal professions, and representatives of parent organizations participated in the Sixth National Conference on Child Abuse and Neglect in Baltimore, MD. The theme of the conference was "A Commitment to Children: Strengthening Families, Communities and Services."

Organized by the National Center on Child Abuse and Neglect, Office of Human Development Services, HHS, the conference was cosponsored by 25 national, local and state organizations concerned with the welfare of children. Attendees discussed the protection of children in residential institutions, abused and neglected children with developmental disabilities, and other subjects dealing with the abuse of children in general.

Tapes of over 100 sessions covering a wide range of topics featured at the conference will be available for sale. A price list may be ordered from: Dc Tech, 4865 Cordell Avenue, Bethesda, MD 20814, (301) 951-0333.

Proceedings of the conference will be available in January and can be ordered by contacting: Junior League of Baltimore, 4803 Roland Avenue, Baltimore, MD 21210.

#### Proposed R&D Priorities Published

The Office of Human Development Services (OHD), HHS, published in the August 29, 1983, *Federal Register*, a notice of proposed FY 1984 child abuse and neglect research and demonstration activities to be considered for support as a part of the OHD coordinated discretionary program. After consideration of the comments, which were due October 28, regarding the above notice, final child abuse and neglect priorities will be announced and will be carried out by the National Center on Child Abuse and Neglect, Children's Bureau, P.O. Box 1182, Washington, DC 20013.

Among the 15 research and demonstration priorities being considered are two that are specific to handicapped children: 1) Development of Procedures for Ensuring Protection for Handicapped Infants—states have had to deal with instances of medical, nutritional and social service neglect of impaired infants. The development of model procedures to ensure appropriate child protective action for national dissemination has been identified as an important area. 2) Collaborative Approaches to Addressing Needs of Preschool Handicapped Abused and Neglected Children—there is evidence that there is a higher incidence of abuse and neglect in children with handicapping or disabling conditions. The major difficulty experienced by Child Protective Service (CPS) workers appears to be

the identification and selection of specific service providers to treat the children and the establishment of an effective client and service provider feedback mechanism. Information about how to work with a consortium of programs and providers at the community level (CPS, Headstart, public school systems, regional mental health centers, medical facilities and group or individual practitioners) to implement an integrated referral and monitoring system for abused and neglected children with handicapping or disabling conditions is needed.

The other 13 priorities under consideration for FY 1984 deal with improved services for abused and neglected children through child protective service agencies, the public school system, juvenile courts and community-based programs.

OHD anticipates that the program announcement for the coordinated research and demonstration program will be published in the *Federal Register* later this year. The R&D projects conducted by the National Center on Child Abuse and Neglect are a part of their activities designed to assist and enhance national, state and community efforts to prevent, identify and treat child abuse and neglect.

#### Clearinghouse Produces Bibliographies

The Clearinghouse on Child Abuse and Neglect Information (operated by Herner and Co., 1700 North Moore Street, Arlington, VA 22209, telephone: (703) 558-8222) offers two annotated bibliographies, *Physically Handicapped Children and Child Abuse and Neglect* and *Mental Retardation and Child Abuse and Neglect* which are updated semiannually.

The bibliographies cover articles in professional journals, books and program descriptions. They comprise a wide range of topics which illustrate the complexity of the connection between disablement and child abuse and neglect. Researchers looked into the cause and the role the handicapped child plays in triggering abuse and neglect and they have looked at handicapping conditions as the result of abuse and neglect. They studied the characteristics of the abusing parents, their use of drugs, and their past history of having been an abused or neglected child. Studies have been done on the language deficit of abused and neglected children, on the beneficial effects of play therapy, and on the connection between juvenile delinquency and handicapped abused children. There are discussions of court cases, parents fighting the termination of their parental rights because of abuse and neglect, and the vulnerability of handicapped children, especially retarded and blind children, to sexual exploitation. Several articles review existing literature both on the family with a handicapped child and on the role of the disabled child in abuse and neglect. The bibliographies cover roughly the literature of the past decade.

## HHS Awards New Grants

Health and Human Services Secretary Margaret M. Heckler recently announced the award of almost \$2 million in grants to improve care for handicapped children.

The Maternal and Child Health Block Grant funds, set aside for special projects of regional and national significance (MCH/SPRANS), support a wide variety of activities recommended by a Workshop on Children with Handicaps and Their Families, held in December 1982. The Workshop was called by C. Everett Koop, M.D., Surgeon General of the U.S. Public Health Service, who realized that the lives of many handicapped children are being saved through the revolutionary transformations in medical technology of the last four decades, but that community support services for the children and their families are often lacking or not visible.

The participants in the Workshop included health professionals, financing experts, consumer representatives, patients and families, and local, state and Federal government officials. They concentrated on the severe, specific problems of the ventilator-dependent child, and the findings for this prototype were extrapolated for their implications for all handicapped children.

The major objectives of the Workshop were: 1) to examine the problem of service delivery to handicapped children and their families in order to develop strategies for providing community-based services as an alternative to acute care facilities; and 2) to examine current funding mechanisms for providing services in order to develop new strategies of improving financing for safe, appropriate, and cost-effective health care for these children and their families in nonacute care facilities.

The activities supported by the MCH/SPRANS grants include development of new standards of care that better reflect family needs and quality of life for the disabled child, development of regional care systems to help transfer children out of institutions and into home or home-like settings, as well as data collection and information sharing. The new grants were awarded as follows:

- The University of Iowa and Michigan State University received awards to develop standards of care that, as recommended by the Workshop, will be innovative, focus on the needs of the family and reflect concern for the quality of life for each disabled child. The Iowa project, funded at \$115,403 in FY 1983, will consider children with all kinds of disabling conditions; and the Michigan project, funded at \$130,000, will focus on children with diabetes.
- Three MCH/SPRANS grants were awarded to develop systems of regionalized care with a focus on ventilator-dependent children. All three projects intend to transfer children from institutional settings to home or home-like settings by developing and sustaining community support systems. The grantees are: Crippled Children's Program at the University of Illinois, \$190,000; Children's Hospital, New Orleans, LA, \$136,019; and Maryland State Department of Health and Mental Hygiene, \$190,000.
- Six MCH/SPRANS Grants were given to facilitate the

development of regionalized juvenile arthritis centers. The grantees are: National Jewish Hospital, Denver, CO, \$142,310; Emory University, Atlanta, GA, \$75,000; Children's Medical Center, Honolulu, HI, \$150,000; La Rabida Children's Hospital, Chicago, IL, \$130,000; Medical Center, Cincinnati, OH, \$125,000; and Texas State Department of Health, \$125,000.

- Health Research, Inc., in New York City, received \$140,000 to develop a system of data collection and coordination of care to children with chronic illnesses which can be replicated throughout the State of New York.
- The University of Iowa received \$160,000 to continue the networking of services along the lines earlier developed in an Iowa model.
- The National Center for Clinical Infant Programs in Washington, DC, was awarded \$124,977 for "Project Zero to Three," which is designed to assist ten selected states in their efforts to improve services for at-risk and disabled children aged 0-3 and their parents. The project will explore ways to share knowledge and to build consensus among professionals through meetings, consultations and technical assistance.

Copies of the *Report of the Surgeon General's Workshop on Children with Handicaps and Their Families* are available without charge while supplies last from: National Center for Education in Maternal and Child Health, 3520 Prospect Street, N.W., Washington, DC 20007, (202) 625-8400.

## Transition

(Continued from page 11)

ized vocational skill training. Like the Gallaudet program, job readiness and advancement potential are markedly increased for the students through the acquisition of reading, writing and arithmetic skills. Competency in the three R's provides a solid base upon which the superstructure of specialized skill training can be built.

The addresses for the above programs are:

Jake Maness and Diane Perrele  
Marist College  
892 North Road  
Poughkeepsie, NY 12601

Nancy Pollock  
Adult Basic Education Program  
Gallaudet College  
800 Florida Avenue, N.E.  
Washington, DC 20002

Rosemary Lareau  
Maryland Rehabilitation Center  
2301 Argonne Drive  
Baltimore, MD 21218

Polly Brown  
Woodrow Wilson Rehabilitation Center  
Fishersville, VA 22939



## News Briefs

### DD Children and the HHS Adoption Initiative

Earlier this year, HHS announced a national effort to promote activities which would move special needs children out of foster care into permanent adoptive homes. The Department recently focussed its activities on the adoption of children with developmental disabilities.

Dorcas R. Hardy, Assistant Secretary for Human Development Services, HHS, leads the Department's adoption initiative. Hardy recently participated in a Special Needs Adoption Workshop, along with Clarence Hodges, Commissioner for the Administration for Children, Youth and Families, and Laurie Flynn, Executive Director, North American Council on Adoptable Children. Workshop participants discussed methods to increase cooperation between child welfare workers and local developmental disability groups, to foster recruitment and public awareness of special needs adoptions, and to use available adoption subsidies.

The Office of Human Development Services recently published a newsletter, *Adoption Notes*, which was devoted almost entirely to the topic of adoption of developmentally disabled children. The newsletter cited various publications, films, television programs and projects around the country which focus on developmentally disabled children.

This special issue of *Adoption Notes* is available from: Office of the Assistant Secretary for Human Development Services, Attn: Pat Wood, Room 309F Hubert Humphrey Building, 200 Independence Avenue, S.W., Washington, DC 20201.

### ADD Reorganization Announced

A new Statement of Organization, Functions, and Delegations of Authority for the Administration of Developmental Disabilities (ADD), Office of Human Development Services, Department of Health and Human Services, was published in the October 27 *Federal Register*. The purposes of the new notice are: 1) To reduce the Administration of Developmental Disabilities from five divisions to three by removing the public affairs function (centralized at HDS level) and placing the management services functions under a small staff in the Office of the Commissioner; and 2) to consolidate the functions of the ten regional offices on Developmental Disabilities into four expanded area offices.

The Regional Offices on Developmental Disabilities are now located in Regions III, VI, VII, and IX. The areas designated by the standard Federal Regions are covered by the DD Regional Offices as follows: Regions I, II, and III by Region III, Philadelphia, PA; Regions IV and VI by Region VI, Dallas; Regions V, VII, and VIII by Region VII, Kansas City, Mo; and Regions IX and X by Region IX, San Francisco. Each office, under the direct supervision

of the Regional Administrator, serves as the administrative focus between the Central Office and State and local governments and other organizations for the consideration of program issues and policies affecting service needs and rights of developmentally disabled persons.

### 1984 Increase in Medicare Payments

The Department of Health and Human Services has announced that because of continuing increases in health care costs, payments by Medicare beneficiaries will automatically increase again in 1984. The increases are required under 1986 Medicare law, and they affect beneficiary payments of hospital deductibles, coinsurance and monthly premiums.

Under Medicare Part A (hospital insurance), the deductible patients pay for hospitalization will increase from \$304 to \$356 on January 1, 1984. The rise in this deductible also increases the amount of coinsurance beneficiaries must pay if they remain in the hospital for more than 60 days during 1984. The rate the patient must pay for a stay of more than 20 days in a skilled nursing facility is increased.

Under Medicare Part B (supplementary medical insurance), the basic premium will rise from \$12.20 to \$1 a month, January 1, 1984, under the Social Security Amendments of 1983.

About 30 million people are covered under the Medicare program. In 1984, the number of enrollees is expected to grow to about 30.5 million. Medicare spending is expected to increase from \$56.1 billion in FY 1983 to \$64.7 billion in FY 1984.

The new rates were published in the *Federal Register* for September 30, 1983 on pages 44912-44917.

### New HHS Service to Hispanic Radio Stations

A new service especially aimed at Hispanic radio stations across the country has been announced by Margaret M. Heckler, Secretary of the Department of Health and Human Services. A toll-free 800 line will afford the stations an opportunity of receiving from HHS vital health and social services information in Spanish.

This new service, expected to be in operation within the next few weeks, is the result of a survey of Hispanic radio stations to determine the kinds of information needed and the best way to deliver it. There are some 400 radio stations in the country that broadcast in Spanish or have significant portions devoted to Spanish broadcast.

As soon as the new toll-free line is set up, stations will be contacted and given specific information on the availability of weekly news, features and public service announcements.

## News Briefs

### FY 1984 Appropriations Legislation Signed

The Fiscal Year 1984 appropriations legislation for the Departments of Labor, Health and Human Services, and Education and Related Agencies was signed into law by the President on October 31. The agencies had been operating under a Continuing Resolution which was due to expire on November 10. The Clearinghouse will report on funding levels for the major programs concerning the handicapped in the next issue of Programs for the Handicapped.

### NTID Dedicates New Facility

A new academic building has recently been dedicated at the National Technical Institute for the Deaf (NTID) at the Rochester (NY) Institute of Technology.

The 30,000 square foot facility contains classrooms, laboratories, and offices. It was designed to help NTID accommodate an influx of students born deaf as a result of a rubella epidemic in the early 1960's. The location provides easy access to other facilities on the RIT campus to further promote the integration of deaf students and their hearing peers. RIT's deaf students also benefit from nearly 200 other technical and professional courses of study offered by RIT's other eight colleges.

The new facility was named for Hugh L. Carey, former U.S. Congressman and New York State governor, who was one of the authors of the legislation that created NTID at RIT, which is funded by the U.S. Department of Education. It represents the world's first effort to educate large numbers of deaf students within a college campus planned primarily for hearing students. More than 1,000 deaf students study and reside on the RIT campus.

### Cooperative Efforts in Arts Education Announced

The National Committee, Arts for the Handicapped (NCAH) and the Alliance for Arts Education (AAE) have announced new cooperative efforts to assure that every student, abled or disabled, is allowed access to the avenue of self-expression found in the arts.

Both NCAH and AAE are educational affiliates of the John F. Kennedy Center for the Performing Arts. NCAH is the nation's coordinating agency for arts programs for disabled individuals, involving over 400,000 handicapped persons. Founded in 1974, NCAH now supports year-round programs in 50 states, the District of Columbia and Puerto Rico. AAE promotes arts curricula in our nation's schools. Other major emphases are on the development of state plans for comprehensive arts education, technical training and assistance, and arts education on the state and community level.

For more information, contact: National Committee, Arts for the Handicapped, Education Office, John F. Kennedy Center for the Performing Arts, Washington, DC 20565, (202) 332-8960.

### Shoe Exchange Now Computerized

The National Odd Shoe Exchange, a nonprofit service for people who need two different size shoes because of birth defects, polio, injury, amputation or illness, has computerized its membership files so that a shoe match can be made in a matter of seconds.

The function of the Exchange is to serve as a clearinghouse, to bring together those persons with mutual problems and to aid them in securing properly sized shoes. At present there are 14,000 registered members from all over the world, who are matched according to size, age and taste in shoe styles. In addition to putting members in touch with one another, the Exchange receives tax deductible donations of mismatched shoes from shoe stores all over the country. The Exchange is now encouraging shoe manufacturing companies and stores to begin selling mismatched shoes.

For further information about the Exchange or its newsletter, *The Exchange News*, contact: National Odd Shoe Exchange, Rural Route 4, Indianola, IA 50125, (515) 961-5125.

### New Electronic Device For Vision Impaired

Viewscan, a portable electronic magnifying reading system for people with low vision, is now available from Telesensory Systems, Inc., an organization that was established in 1971 to design, manufacture, and distribute electronic aids to minimize the limitations imposed by physical disabilities.

People with low vision had often asked for a device comparable to the Optacon, a portable reading machine used by totally blind individuals, or a portable read/write system like the VersaBraille system, also distributed by Telesensory Systems, Inc.

The Viewscan is manufactured by Wormald International Sensory Aids. By scanning a small hand-held camera across the page, the Viewscan user can see a bright, magnified image of the text on the neon matrix display screen. The system fits inside a briefcase. By connecting the device to a minicomputer, it becomes the Viewscan Test System, giving the user the ability to take notes quickly and read them on the spot.

For further information, contact: Telesensory Systems, Inc., P.O. Box 7455, Mountain View, CA 94039-7455, (415) 890-0920.

## Announcements

### ACLD International Conference Announced

The Association for Children and Adults with Learning Disabilities has announced the 1984 ACLD International Conference to be held at the New Orleans Hilton Hotel on February 28-March 2, 1984. The theme of the Conference is "Tradition, Renewal, Change." A preliminary program listing workshops, training courses, and sessions, and housing, registration and travel information is available from: Association for Children and Adults with Learning Disabilities, 4156 Library Road, Pittsburgh, PA 15234, (412) 341-1515.

### Special Education Conference And Call for Papers

The American Association of Special Educators, Inc., has announced the 7th Anglo American Special Education Conference, to be held at Chelsea College in London, July 2-3, 1984, and has issued a Call for Papers and Exhibits. The Conference theme will be "Educational Trends and Developments in U.S. and UK" and "The Future of Computers in Education."

Highlights of the tour to the UK will include attendance at the Conference, various school visitations and seminars, and receipt of college credits, and income tax deductibility for educators.

Information on papers and exhibits should be forwarded to: Louis Marpet, American Association of Special Educators, 107-20 125th Street, Richmond Hill, NY 11419, (212) 841-1224. Reservation forms are available from AASE Tours at the above address.

### Special Services at Metropolitan Opera

The Metropolitan Opera Guild Education Department sponsors the outreach education programs of the Metropolitan Opera Association. Through its programs and materials, opera is made accessible to people of all ages and backgrounds.

An infrared listening system has recently been installed at the Metropolitan Opera House to provide greater clarity and intelligibility of performances for hearing-impaired audiences. Services for blind and visually handicapped persons include: program notes on cassette and in braille detailing all Metropolitan Opera productions, libretti in large print and braille for operas in the Met repertoire, score desk seats, backstage tours, and selected Opera News magazine articles in braille.

For further information, contact: Debra Yancov, Special Services Coordinator, Metropolitan Opera, Lincoln Center, New York, NY 10023, (212) 582-7500, ext. 464.

### AAMD Announces Annual Conference

The American Association on Mental Deficiency (AAMD) has announced its 108th Annual Meeting to be held May 27-31, 1984, at the Hyatt Regency Hotel in Minneapolis, MN.

AAMD, founded in 1876, is an interdisciplinary professional and scientific organization dedicated to mental retardation. Although the membership represents a wide variety of professions from different parts of the world, it has maintained a strong unity of purpose: to seek for mentally retarded persons the right to develop their potential to the maximum; to satisfy fully the needs of their personalities; and to become, as far as possible, independent and useful members of the community.

The 107th Annual Meeting was attended by 1,800 persons, with 700 speakers and 40 exhibitors.

Copies of the Preliminary Program for the 108th meeting, including housing and registration forms, are available from: AAMD, 5101 Wisconsin Avenue, N.W., Washington, DC 20016, or call toll-free, (800) 424-3888.

### Technology and Media Organization Formed

A new international organization, Technology and Media for Exceptional Individuals (TAM), has been formed to promote closer relationships among educators and others concerned with the application of technology to meet the needs of handicapped children and adults, the gifted, and the aged. TAM has applied to become a Division of the Council for Exceptional Children.

In announcing the new organization, TAM said that "technology and media are having a dramatic impact on general education and hold important implications for the fields of special education, rehabilitation, geriatrics. The ability of handicapped individuals to function in our society can be greatly enhanced by the use of technological tools for education and daily living. Computers, telecommunication devices, cable TV, robotics, and other new developments can help exceptional individuals to lead normal lives."

TAM will publish a journal and newsletter and conduct training programs, conferences, and workshops. It also plans to review and field test equipment and software, and will cooperate closely with education and government agencies and with business and industry in research, demonstration, and review of technology applications.

Further information and a membership application to join TAM are available from: Charles (Skip) MacArthur, Membership Chairperson/TAM, Institute for the Study of Exceptional Children, Department of Special Education, University of Maryland, College Park, MD 20742, (301) 454-5427.

## Announcements

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### Sibling Seminar Announced

The Second National Seminar dealing with Siblings of Developmentally Disabled Persons will be held on May 3-4, 1984, in New York City. The sponsors of the seminar are Kean College of New Jersey, the New York City Association for the Help of Retarded Children, New York University School of Social Work, and the Mental Retardation Institute.

The seminar will focus upon current developments in research and service, and will seek to involve siblings, parents and professionals in the deliberations. Papers dealing with these concerns are being sought by the Planning Committee. Interested individuals and groups should contact: Mayer Schreiber, D.S.W., Chair, Planning Committee, Sibling Seminar, Kean College of New Jersey, Union, NJ 07083, (201) 527-2090.

The proceedings of the First National Seminar will be available by January 1, 1984. A check for \$6 payable to NYC AHRC may be sent to: Lucy Garcia, NYC Association for the Help of Retarded Children, 200 Park Avenue South, New York, NY 10003.

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### Request for Information

The Human Services Research Institute in Boston requests assistance in locating examples of needs assessment methods used at the state or local level to estimate the housing needs of handicapped individuals (i.e., physically handicapped, mentally retarded/developmentally disabled, and chronically mentally ill persons). Selected methods will be summarized in a resource book supported by the U.S. Department of Housing and Urban Development.

In describing a method, the Institute requests summary information on: 1) organization responsible for completing the assessment; 2) impetus for completing the assessment; 3) types of information available from the employed method (descriptions of the size of the eligible handicapped population, existing living arrangements, housing types required, and availability of housing to meet requirements); 4) sources used to secure needs assessment information; 5) resource requirements; 6) time considerations; 7) validity and reliability checks conducted on the method; 8) political or organizational constraints; 9) other.

Available descriptions will be accepted in any format. Submit summaries to: Valerie J. Bradley, Human Services Research Institute, 120 Milk Street, Eighth Floor, Boston, MA 02109, (617) 542-1812.

### Voice Indexed Dictionary

By the end of this year, people who are unable to read print will have access to a recorded dictionary titled *First Recorded Dictionary for the Blind Uses New Technology*. This recorded version of the Concise Heritage Dictionary, containing over 55,000 entries, employs a new information retrieval technology for the blind known as voice indexing. When a cassette tape player (which are distributed by the National Library Service for the Blind and Physically Handicapped to its patrons) is placed in the fast-forward mode of operation, one normally hears the unintelligible scream of highly speeded-up speech. In a voice-indexed cassette, however, understandable normally-pitched index words are superimposed over the fast-forward chatter. This allows individuals to quickly locate desired material by listening to the string of index terms while the tape is at high speed. When the desired term is heard, the tape is returned to the normal playing mode and the full text is heard. The Dictionary, which is recorded on 56 four-track cassettes, took two years to complete and involved thousands of hours of narration time. It is expected to be available within the next few weeks to NLS borrowers through the national network of cooperating libraries. It will also be available for purchase at \$82.50 from the American Printing House for the Blind, P.O. Box 6085, Louisville, KY 40206. The catalog number is C-1090.

Other books recorded by the NLS using voice indexing include: *Access to National Parks: A Guide for Handicapped Visitors*, *Boy Scout Field Book*, *Cooking for Myself*, *Everyone's Money Book*, *Music Business Handbook and Career Guide*, and others.

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### Braille Research

The *Braille Research Newsletter* is a periodic newsletter devoted to providing the latest, state-of-the-art information on the production and use of the Braille reading system throughout the world. Written for the lay and professional person, the Newsletter reviews new equipment, discusses new or innovative programs, describes the results of Braille-related research projects, and provides resource listings of manufacturers of various Braille devices. The present issue (#14) contains such articles as "Cognitive Processes in Braille Reading," "Telebraille: The New Telecommunication System for Deaf-Blind People," "Tactile Diagrams," "Braille Stereotypes and Dupliators," and others. To request issue #14, send \$6 (specify print or braille) to: National Braille Press, Inc., 88 St. Stephen Street, Boston, MA 02115.

## NEW PUBLICATIONS

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### LEGAL ADVOCACY

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*Accommodating the Spectrum of Individual Abilities* is a monograph prepared by the U.S. Commission on Civil Rights, based upon a two-day consultation the Commission held on "Civil Rights Issues of Handicapped Americans," during which they met with nationally recognized experts. The book is intended to provide overall guidance to those charged with interpreting and applying handicap nondiscrimination requirements. It focuses on the issue of reasonable accommodation because of its central importance to handicap discrimination law. Part I provides basic information about handicapped people, the barriers they face, and their legal rights. Part II suggests ways to resolve legal issues concerning handicap nondiscrimination requirements. The authors draw upon volumes of literature in the civil rights for the handicapped field, citing titles and additional text through extensive use of footnotes. Single copies of this 180 page monograph are available without charge from: U.S. Commission on Civil Rights, Publications Warehouse, 821 N. Payne Street, Alexandria, VA 22314, (703) 557-1794. (As of 10/28, the Commission had not received an appropriation for FY 1984 funding. *Programs for the Handicapped* will report on any change in source for the above publication.)

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*Rights and Advocacy for Retarded People* by Stanley S. Herr is an analysis of the movement during the last decade for legal and human rights for mentally retarded people, concentrating on three goals: to help retarded people avoid admission to institutions; to gain protection from physical and psychological harm; and to secure opportunities for community living, including appropriate housing, education, and social services—the elements of normal life. It discusses the typical institution for the mentally retarded, and the ways policies have been adjusted to reflect the concerns of professionals, the public and the families of mentally retarded persons. It examines the legal changes that have resulted at federal and state levels regarding the operation of the institutions. There are chapters on the rights of retarded persons to the least restrictive modes of care, to appropriate, individualized habilitation and education, and to community reintegration. The book discusses the need for an independent advocacy system, and proposes a model for securing trained advocates for mentally disabled persons now living in central facilities as well as in geographically dispersed locations. The final chapter addresses the limits of legal reforms and the unfinished agenda for the advocates for mainstreaming the mentally retarded people. This 265 page hardcover book is available at \$28.95 from: Lexington Books, D.C. Heath and Company, 125 Spring Street, Lexington, MA 02173.

*Legal Rights and Mental Health Care* by Stanley S. Herr, Stephen Arons, and Richard E. Wallace, Jr., is intended as a guide to the process of mental health legal advocacy and the rights of persons receiving mental health care. Although written primarily for mental health practitioners, it will prove useful to other mental health professionals, clients, advocates, and interested citizens. It provides a summary of basic legal theories and client rights in the mental health system. It identifies advocacy approaches and legal rights that can augment the principles of autonomy and social integration. Part I describes the nature of advocacy in mental health systems and the interrelated issues of competency, consent, and client participation. Part II sets forth rights in the mental health treatment process, including the right to treatment, the right to refuse treatment, the principle of the least restrictive alternative, and the rights to privacy, confidentiality, and access to records. Part III discusses rights to community services, including some special problems and right of children, guardianship and other protective services, and nondiscrimination and the promise of equal opportunity. The final chapter describes ways in which clinicians can assist those they serve to exercise their rights and opportunities. This 190 page hardbound book is available at \$22.95 from: Lexington Books, D.C. Heath and Company, 125 Spring Street, Lexington, MA 02173.

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### EDUCATION AND AUTISM

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*Teaching Autistic Children to Communicate* by Paige Shaughnessy Hinerman, is intended for speech clinicians, special education teachers, program directors and therapists who work with autistic and communicatively impaired children. The author is the former director of the Utah Program for Autistic Children, a federal demonstration project and group home for young autistic children, who developed the step-by-step guide to help autistic children learn to attend to instruction, develop social relationships and master basic communication skills. The book includes directions for teaching autistic children to "pay attention," methods for determining their capacity for verbal communication, and directions for teaching both verbal and nonverbal communication. It provides answers to questions such as: What words should I teach? At what point should I start teaching manual communication? Which sign language course should I use? How should I document progress? What help can I expect from parents? What can I do to increase target behavior? What factors are most critical for success? Copies of this 210-page hardbound book are available at \$24.95 each from: Aspen Systems Corporation, P.O. Box 6018, Gaithersburg, MD 20877, (800) 638-8437 or in Maryland 251-5233.

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## Wheelchair Exercises

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The *Wheelchair Workout with Janet Reed* presents a 30-minute program of exercises for wheelchair-bound individuals. The package contains a 42 page *Information Manual* and an audio-cassette tape. The program incorporates elements of aerobic, isotonic, and isometric movements and is divided into three parts: warm-up, workout, and cooldown. Exercises are designed to increase muscle strength, endurance, and flexibility, and can all be performed in a seated position. The *Information Manual* provides illustrated instructions for carrying out the exercises, and provides information on nutrition and physical fitness in general. The cassette contains the actual exercise session with musical accompaniment. The package is available for \$13.50 plus \$1 postage and handling inside the U.S. (\$2 from outside the country) from: Wheelchair Workout, 750 South 23rd Street, Arlington, VA 22202, or for further information, call (301) 279-2994.

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## MR Institutions

(Continued from page 10)

By dispatching the HCFA team to make a detailed, formal inspection of the Massachusetts facilities, Secretary Heckler laid the groundwork for what she said she hopes will never happen, "a cut-off of federal funds to my home State. But Massachusetts has had a decade to bring itself into compliance with federal standards. The legislature has the future of these schools and the people they serve in its hands. I urge the legislature to appropriate the necessary funds so that the federal government can continue to do its financial part."

Decisions concerning what action is necessary to bring the facilities into compliance will be made after the HCFA team has made its report to the Secretary—taking into account funds appropriated by the state legislature to correct outstanding areas of noncompliance.

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## Psychosocial Rehabilitation: A Video Series

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A picture is worth a thousand words! For people who have wished for pictorial documentation of programs—seeing people in action, listening to conversations between clients and counselors, talks between employers and placement specialists—a new video series, "Approaches in Psychosocial Rehabilitation," should be the answer.

The series was produced by Fellowship House, South Miami, Florida. It shows the effectiveness of psychosocial methodologies and management of a community support network for rehabilitation of severely emotionally disabled adults. The series is in eight parts, each showing an important facet of the process: 1) Introduction to Psychosocial Programs; 2) Staff Role: the Generalist Model; 3) Social Rehabilitation Program; 4) Prevocational Rehabilitation Program; 5) Transitional Employment; 6) Residential Continuum in the Community; 7) Parents and Concerned Friends Organizations; and 8) Involvement of Community Groups.

Fellowship House, a not-for-profit organization, provides comprehensive services to severely emotionally disabled adults. Its philosophy, based on the principles of Fountain House in New York, is to assist club house members to learn and improve societal skills leading towards independence in the community and providing them social support services of indefinite duration. Staff and club members played themselves and helped to make the series as close to life and as informative as possible.

Each videotape contains a narrated documentary portraying one specific program and a discussion section on management issues. A printer user guide accompanies each video tape. Individual tapes cost \$195; the entire series, \$1250. Inquiries should be addressed to: Fellowship Foundation, 5711 South Dixie Highway, Miami, FL 33143, (305) 667-1036.

**NEW PUBLICATION  
from the  
Clearinghouse on the Handicapped**

The 1983 edition of the **Pocket Guide to Federal Help for the Disabled Person** is now available from the Clearinghouse. This consumer booklet outlines the government benefits and services and tells handicapped individuals where to apply.

Single or multiple copies are available without charge. Organizations that serve handicapped individuals are encouraged to order copies for their members and to notify their affiliates of the booklet's availability. Send a **self-addressed mailing label** to: Clearinghouse on the Handicapped, U.S. Department of Education, Room 3119 Switzer Building, Washington, DC 20202, (202) 245-0080.